Perceived Organizational/Institutional barriers to breastfeeding in Appalachia among lactation consultants, counselors and providers

by

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Introduction

The US Centers for Disease Control and Prevention (CDC) and American Academy of Pediatrics recommend exclusive breastfeeding for six months and continued breastfeeding for at least 12 months because of its health benefits to children and women (CDC, 2019). Less breastfeeding is associated with childhood infections, decreased intelligence, increased risk of overweight and diabetes, breast/ovarian cancer prevention, and type 2 Diabetes (Victoria, et al 2016). One objective of the Healthy People 2020 was to increase proportion of infants who breastfed at 6 months to 60.6%. Yet, this proportion is currently below the target at 57.6% (CDC, 2019). Despite increases in breastfeeding rates nationally, rural Appalachia has a lower prevalence of breastfeeding of 57.5% compared to the rural national breastfeeding prevalence of 68.7% (Wiener & Wiener, 2011), leading to poor health outcomes. Appalachia includes 13 states and 420 counties and has extensive health disparities, barriers to care, and various other determinants including low access to healthcare, low income, high poverty rates etc. compared to the nation as a whole (PDA, Inc et al 2017). Hospital practices such as those followed by baby friendly hospitals are shown to improve breastfeeding practices (Munn et al 2016). Healthcare providers, peer counselors and breastfeeding groups that counsel women about breastfeeding are also shown to improve breastfeeding practices (Sinha et al 2015). However, accessing lactation providers and support is particularly difficult in Appalachia (Ray et al 2018).

Lactation support can improve breastfeeding practices. Understanding the experiences of those who provide lactation support is critical, yet there are few studies that have explored their experiences. Although there are a limited number of studies that have explored perspectives of lactation counselors in providing breastfeeding support in the U.S. (Anstey et al.,2017), a review of the literature did not reveal any that are focused exclusively in the Appalachian region. The

Lactation Consultants' Perceived Barriers study that interviewed lactation consultants across Florida, for example, identified a set of direct and indirect barriers such as institutional constraints, lack of coordination, poor service delivery, limited social support, low self-efficacy, social norms, and lack of breastfeeding knowledge and attitudes (Anstey et al.,2017). Because of the unique characteristics and culture of the Appalachian region, it would be beneficial to examine perspectives of lactation providers and supporters in the Appalachia to explore the low rates of breastfeeding in this region. While the facilitators and barriers women have experienced with regards to receiving breastfeeding support in 19 Appalachian counties was conducted among 176 women that shared their experiences (Raffle, Ware, Borchardt, & Strickland, 2011), research on the experience of providers is lacking. The goal of this study is to explore experiences and perspectives of providers that support breastfeeding/lactation among women in the Appalachia, with a focus on organizational/institutional and provider level barriers in this area.

It is important to understand the experience of these providers to improve breastfeeding rates in the Appalachian region. The purpose of the current implementation research study is to examine the experience of providers supporting families with breastfeeding and lactation in Appalachia. There is limited data about the organizational/institutional barriers to breastfeeding in Appalachia. The critical period of hospital stays and mother and newborn experiences there exert influence on early breastfeeding initiation and establishment of breastfeeding (CDC Guide to Breastfeeding Interventions, 2005). Additionally, breastfeeding education as a part of prenatal education in hospitals and clinic settings is found to be the most effective intervention for increased breastfeeding initiation (CDC).

Study objective and aims

The objective of this study was to explore organizational/institutional barriers that lactation consultants, providers and counselors (LCPCs) face when providing breastfeeding support to families in the Appalachian region.

Aim 1: Identify the key organizational/institutional barriers providers face when providing breastfeeding/lactation support in the Appalachian region through an online survey.

Aim 2: Examine provider experiences and perceptions of the organizational/institutional barriers to providing breastfeeding and lactation support to families in Appalachia through in-depth phone interviews, and to gain a sense of changes LCPC's would like to see in their communities.

Methods

Quantitative Methods

Sample

The Appalachian Breastfeeding Network is a network of members interested in supporting the work towards transformation of breastfeeding culture in Appalachia by providing empowerment, education and accessibility to care. In partnership with the Appalachian Breastfeeding Network (ABN), we invited members of the ABN listserv to participate in an anonymous 'Breastfeeding and Lactation Support in Appalachia' Qualtrics survey. Participants completed the survey between March-July 2019. An invitation with the survey link was sent out to ABN members through an email listserv and posted on ABN social media platforms (Facebook, Instagram, and Twitter). We utilized a convenience sample. We received 130 responses on the survey. Out of these responses, 88 participants do work related to breastfeeding and lactation in Appalachia. Out of the remaining 42 responses, 13 respondents did not complete

the survey and 29 respondents were people that work related to breastfeeding and lactation outside of Appalachia or people that are interested in ABN's mission. We examined responses from participants to assess top challenges of providing breastfeeding/lactation support to clients in the Appalachian region. Additionally, we also examined providers perceptions of key challenges their clients experience related to breastfeeding/lactation.

Data Collection

Questions were formulated as multiple choice, ranking, and open ended on Qualtrics, and were organized into three main sections: demographic characteristics, experience providing breastfeeding and lactation support, and ABN initiatives.

Variable and Measures

Sociodemographic characteristics included age, gender, location of work, education, self-identified ethnicity, employment status, and profession. The listed question and answer options for the survey are included in Appendix 1.

Participants were also asked if they were health professionals and what kind of professions they were involved in. We also asked participants whether their work with breastfeeding/lactation was based in Appalachia. We asked participants to choose what setting they provide breastfeeding and lactation in and any breastfeeding/lactation certifications they possess.

The survey asked participants to choose all the challenges they face when providing breastfeeding and lactation support to clients/patients/program participants. Program participants are people who utilize the services given by LCPC's. Out of the challenges they selected, we

asked them to choose the topmost challenge they faced in their communities. Participants were also asked to identify all challenges related to breastfeeding that clients/patients/families in the community experienced. Out of these challenges, participants chose the topmost challenge that clients experienced related to breastfeeding in their communities. We included an open-ended question at the end of the survey so LCPC's could share anything else that was important.

At the end of the survey, participants were asked if they would be willing to participate in a follow-up in-depth interview, and if so, to click on a link to a separate online form where they could enter their contact information separate from their responses.

Analysis

Microsoft Excel was used to generate descriptive statistics.

Qualitative Methods

In order to gain a more comprehensive understanding of the experiences of LCPC's who support families in Appalachia with breastfeeding and lactation, and to explore some of the challenges they experience, we used qualitative methods. We conducted in depth interviews over the phone to gain an understanding of individual LCPC's experiences and identify common themes. We emailed $15 e-gift cards of choice to participants after the interview.

Design

We conducted this qualitative study using semi structured in-depth phone interviews with LCPCs providing breastfeeding/lactation services and support in the Appalachian region.

The goal of the interviews was to hear about diverse perspectives from LCPCs working in a range of different settings to gain a more complete picture of the perceived barriers and difficulties in providing breastfeeding/lactation care in Appalachia. The main questions were developed based on the survey responses and a review of the literature and focused around factors that limited LCPC's ability to provide support to families at the organizational/institutional level, provider level, community/social level, and family level. We also asked interviewees about changes they would like to see in their communities at each level. This thesis will focus on barriers and suggested changes from LCPC's at the organization, institution and provider level.

Sample and Setting

All participants in this study did work or volunteering related to breastfeeding/lactation in the Appalachian region. Participants were a subsample from the Qualtrics survey respondents that showed interest in participating in an interview. The participants that conveyed interest in participating in an interview from the Qualtrics survey sample were contacted by email to schedule a time/date for the interview. Therefore, a convenience sample was used to recruit interview participants. All participants were also connected to the Appalachian Breastfeeding Network and were age 18 years or older and able to speak English.

Data Collection and Analysis

Two researchers (R.S. and G.F.) conducted the phone interviews. Interested participants were contacted through email to set up phone interviews. Interviews were conducted from January 2020 to April 2020; interviews lasted 30-45 minutes each. The in-depth interview guide

is included in Appendix 2. A transcribing software called Recordator was used to record and transcribe all the interviews. Before the interview, all participants gave verbal consent to being recorded. We collected participant interview data anonymously by assigning each participant a numerical identification (R1-R-11; G1-G9).

The transcribed interviews were coded in ATLAS.ti using a rapid qualitative analysis approach and prespecified codes:

1. Factors that limit ability to provide support: Community/Social
2. Factors that limit ability to provide support: Family
3. Factors that limit ability to provide support: Organization/Institutional
4. Factors that limit ability to provide support: Other providers
5. Changes: community/social/family
6. Changes: Organizational/institutional/other providers
7. Main difficulty/barrier

For the purpose of this study, information pertaining to codes 3,4,6, and 7 were analyzed to find common themes with organizational, institutional, provider, and policy level barriers that LCPC's have experienced and changes LCPC's would like to see among organizations, institutions and providers in their communities.

We collected participant characteristics including location (state), BF credentials, current position, age, education, gender and race/ethnicity as part of the interview as well.

Ethical Review

The study was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill. Additionally, permission was received from the President of the

Appalachian Breastfeeding Network. All participants were asked permission to record the interviews and interviewed anonymously. All interviews were conducted in English and transcribed.

Results: Quantitative Analysis

Sample characteristics

The survey was completed by 129 participants. Participant ages ranged of 18-65+ (figure 1). Most participants had a bachelor's degree or a High School Diploma from the sample (Figure 2). About 58.9% of the participants were also Health professionals (Figure 3). The appendix lists what careers are considered as health professions. The breastfeeding credentials of the LCPC's are displayed in figure 3. Interestingly, more than half of the sample worked at WIC or the County Health Department (56.6%) and 26% worked at a hospital (Figure 5). The sample consisted of a predominantly White population (94.6%) (Table 1). There was a wide range in the number of years participants had been providing breastfeeding and lactation support; 24% of the sample had 3-5 years of experience in breastfeeding and lactation support while 26% of the sample had 20 or more years of experience, which helped us gain results from people with little to more extensive experience.

Table 1. Participant characteristics describing race and years of experience (doing work related to breastfeeding/lactation) of the sample

Participant Characteristics	%	Count
Race (N=129; can select multiple)		
American Indian/Alaskan Native	1.6	2
Asian	0.8	1
Black/African American	1.6	2
Hispanic, Latino or Spanish	3.9	5
Middle Eastern/North Africa	0.8	1
Native Hawaiian or Pacific Islander	0.0	0
White	94.6	122
Another	0.78	1
Years of Experience (N=113)		
Less than 1 year	6.19	7
1-2 years	11.5	13
3-5 years	23.89	27
6-10 years	18.58	21
11-15 years	6.19	7
16-20 years	7.96	9
20 or more years	25.66	29

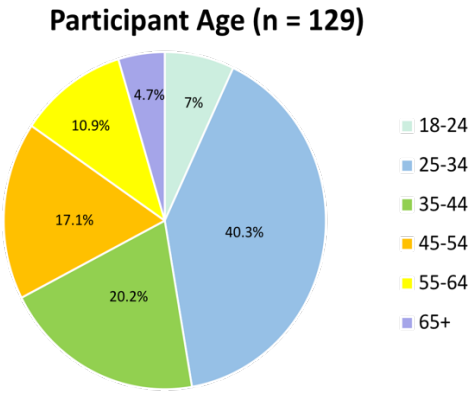

Figure 1. Participant age distribution

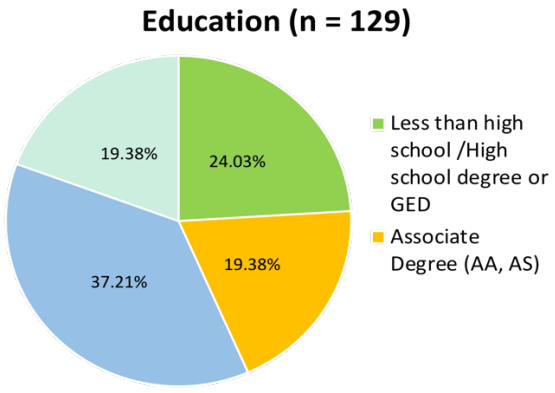

Figure 2. Participant education level

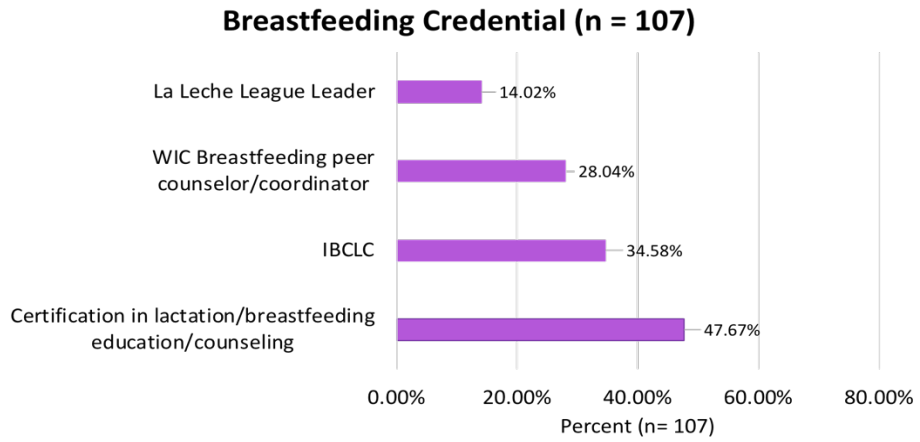

Figure 3. Participant breastfeeding credentials
*IBCLC - International Board-Certified Lactation Consultant
*WIC – The Special Supplemental Nutrition Program for Women, Infants and Children

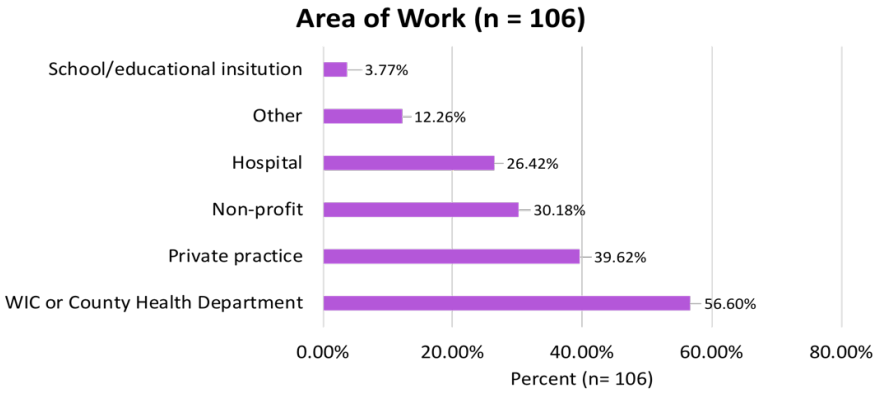

Figure 4. Participant areas of work

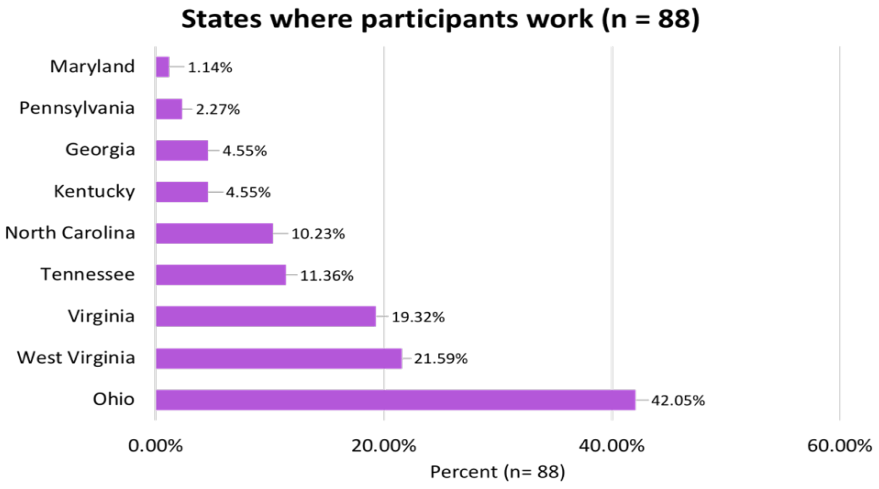

Figure 5. Participant work location by state

All challenges faced by LCPCs

Participants were asked to choose all the organizational/institutional/provider level challenges they faced while providing breastfeeding and lactation support from a comprehensive list of challenges on the survey. Out of the selected challenges, they were prompted to choose the topmost challenge in their respective communities. There were 81 participants that do work/volunteer related to breastfeeding/lactation in Appalachia, that answered this particular question.

In the first round, non-medically indicated supplementation was indicated as one of the challenges that participants faced while providing support in Appalachia by 84% of the participants. Hospital practices, policies and interventions during labor and delivery, was indicated as a challenge by 79% of the participants. Lack of coordination among providers and institutions, and Hospital Postpartum practices, were identified as a challenge by 76.5% of the population (Table 2) These challenges were the top three organizational/institutional/provider challenges identified by majority of the participants. Table 2 displays the rest of the organizational/institutional/provider challenges identified by participants working in Appalachia.

In the second round, there was a lot of variation in the responses when participants were asked to pick the biggest barrier that participants faced providing breastfeeding/lactation support. The following organizational/institutional/provider level challenges were the most selected for the topmost challenge:

1. Non-medically indicated supplementation – 19.8%
2. Hospital postpartum practices – 13.6%
3. Lack of coordination among other providers and institutions – 8.6%
4. Hospital practices/policies/interventions during labor and delivery – 6.2%

5. Supporting clients with concerns about milk supply issues – 4.9%

Non-medically indicated supplementation is giving the recommendation/suggestion to provide babies with formula with no appropriate medical reasoning. Hospital postpartum practices includes lack of skin-to-skin contact, not rooming-in, swaddling, use of pacifiers, use of nipple shields etc.

Table 2. Organizational/Institutional/Provider level challenges that participants identified among all the challenges they faced while providing breastfeeding/lactation support in Appalachia

Challenge	**# of participants**	**% of participants**
Non-medically indicated supplementation	68	84%
Hospital practices, policies, or interventions during labor and delivery (Pitocin, epidurals, forceps, vacuum extractions, cesarean sections)	64	79%
Lack of coordination among other providers and institutions (including lack of referrals, lack of awareness of services by other providers, or delayed follow up, among others)	62	76.5%
Hospital postpartum practices (lack of skin-to-skin, not rooming-in, swaddling, use of pacifiers, use of nipple shields)	62	76.5%
Other health care providers are not supportive of breastfeeding	58	71.6%
Counseling clients around issues related to drug use and lactation/breastfeeding	46	56.8%
Challenges connecting/reaching clients/participants for follow up or retaining clients/participants in programs and services	46	56.8%
Time constraints	35	43.2%
Inadequate staffing	31	38.3%
Supporting clients with infants who are preterm, low-birth weight, or have other health conditions	29	35.8%
Discharge packs provide formula	29	35.8%

Lack of administrative support	29	35.8%
Supporting clients who have health conditions that interfere with breastfeeding/lactation	29	35.8%
Lack knowledge/skills to support clients effectively	13	16%

*81 participants that do work related to breastfeeding in Appalachia answered this question

Provider perceptions of challenges faced by clients/families

Similar to LCPC barriers, participants were asked to choose all the challenges clients and families in their communities faced related to breastfeeding/lactation. Influence of formula industry was identified as one of the organizational/institutional/provider level challenges by 81.5% of participants working in Appalachia. Workplace policies that are not supportive of breastfeeding/lactation was also identified as one of the challenges by 74% of the participants. Lack of support after hospital discharge was identified as another popular challenge by 65.4% of the participants (Table 3). These challenges were the top three organizational/institutional/provider level challenges identified by majority of the participants. Table 3 displays the rest of the commonly identified challenges among clients/families as per LCPC's perception.

When LCPC's were asked to choose the topmost organizational/institutional/provider level challenge that clients/families faced related to receiving breastfeeding/lactation support in their communities, there was considerable variation. A few of the common topmost challenges that were selected included hospital policies and practices interference with breastfeeding initiation (chosen by 4.9% of participants), high cost of lactation support (chosen by 2.5% of participants) and negative influence of formula industry (chosen by 2.5% of participants).

Table 3. Provider perceptions of all Organizational/Institutional/Provider challenges that clients/families face related to breastfeeding/lactation

Challenge	**# of participants**	**% of participants**
Influence of formula industry	66	81.5%
Workplace policies, other than parental leave, that are not supportive of breastfeeding/lactation	60	74%
Lack of support after hospital discharge	53	65.4%
Health care providers are not supportive of breastfeeding	52	64.2%
Routine supplementation in hospitals	50	61.7%
Hospital policies and practices interfered with breastfeeding initiation	48	59.3%
Biased treatment from health providers	42	51.9%
Cost of lactation support	36	44.4%

*81 participants that do work related to breastfeeding in Appalachia answered this question

*Out of the 88 participants that work in Appalachia, only 81 completed these questions. The other 7 participants had incomplete surveys.

Additional Information

At the end of the survey, an open-ended question was asked "Is there anything else that you would like to share with us?" Since the goal of this research is to explore challenges with breastfeeding/lactation in the Appalachia at the organization/institutional level, the following themes were seen in the results.

Health Care provider/Hospital

Participants stressed the importance of Hospital/provider support with breastfeeding to encourage moms to initiate breastfeeding at the hospital. One provider mentioned that hospitals still have a long way to go with breastfeeding support despite the recent support.

"My second child was born at a different hospital that was NOT breastfeeding friendly and gave him a bottle without my consent which caused him to have issues with latching and it took about 2 weeks for us to overcome these issues." – *CLC from Virginia*

"My oldest child is 16 years old, my middle almost 9 and my youngest is 3. I can see a huge difference in hospital practices in the last 16 years and am thankful that hospitals are more supportive of BF now but we still have a long way to go." – *WIC Breastfeeding Peer Counselor, CLC from West Virginia*

"Hospital and pediatric support is lacking at hospital." - *Advanced Practice Nurse, IBCLC from West Virginia*

"Support moms of NICU infants to provide breastmilk. It is very challenging!" -*Advanced Practice Nurse, IBCLC from Ohio*

Lactation education to LCPC's

Increasing access to lactation education for hospitals, providers and LCPC's was also another recurring theme in these responses

"Until the public, the medical profession in particular, is educated and supportive we have an up-hill climb." -*Lactation Consultant at Public Health Department, IBCLC from Ohio*

"I work and live in Maryland, and most of my continuing Ed, policy development, mentor ship and teaching has been in Maryland, but I see great need throughout neighboring West Virginia and Southwestern PA. IBCLCs at my health department are often contacted by residents of surrounding areas looking for assistance. We have successfully "grown our own" by supporting staff with education and mentor ship to become IBCLCs. May be an idea to help other areas improve access to professional lactation support." – *IBCLC from Maryland*

Results: Qualitative Analysis

Sample characteristics

Twenty participants took part in the in-depth interviews. Participants ages ranged from 23-61 years (table 4). Breastfeeding credentials of the LCPCs are displayed in table 4, 50% of

the participants have IBCLCs. 19 of the participants currently do work related to breastfeeding/lactation in the Appalachian region. One participant previously did breastfeeding/lactation work in Appalachia before moving elsewhere for work. The participant population consisted of 80% White and 15% Black/African Americans (table 4). One participant declined to answer age and race. Years of experience varied across the sample and is displayed in table 4. Education level for the participants is displayed in figure 6, where 60% of the participants have a bachelor's degree. Figure 7 displays the states where participants work. About 35% of the participants work in Ohio.

Table 4. Participant characteristics

Participant Characteristics (N=20)	**%**	**Count**
Age		
18-24	10	2
25-34	40	8
35-44	20	4
45-54	10	2
55-64	15	3
N/A	5	1
Race		
White	80	16
Black/African American	15	3
N/A	5	1
Breastfeeding credentials (multiple)		
Doula	5	1
WIC breastfeeding peer counselor/coordinator	35	7
La Leche League Leader	5	1
Certification in lactation/breastfeeding education/counseling	30	6

IBCLC	50	10
Years of Experience		
Less than 1 year	5	1
1-2 years	0	0
3-5 years	25	5
6-10 years	20	4
11-15 years	10	2
16-20 years	20	4
21 or more years	2	4

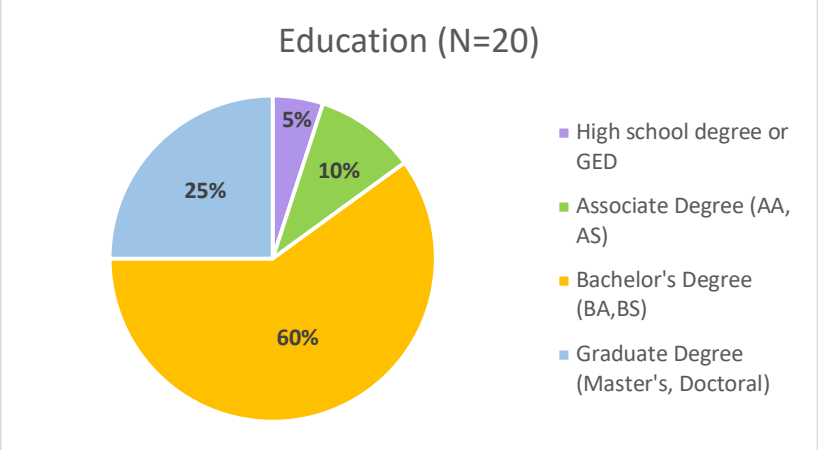

Figure 6. Participant education

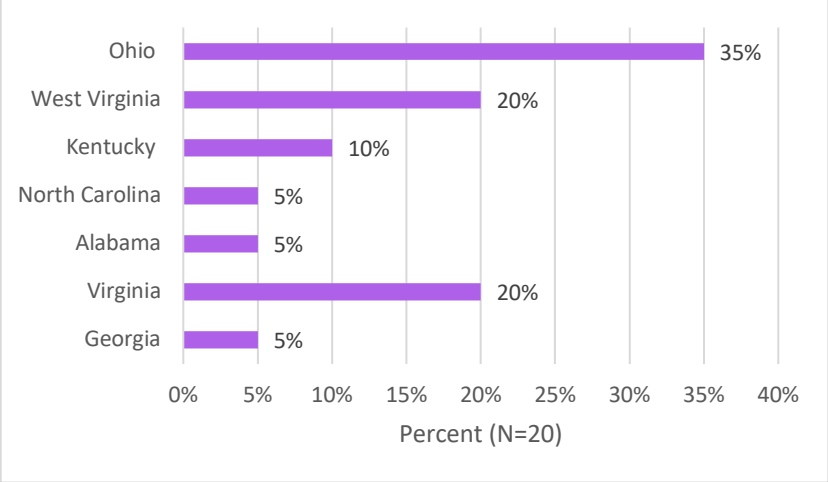

Figure 7. States where participants work

Organizational/Institutional level barriers

Participants were asked to describe some of the organizational/institutional level barriers that impact their ability to provide breastfeeding/lactation counseling and care. Three main

categories of barriers emerged under these results: poor service delivery, poor hiring strategies, and institutional/policy constraints. All the themes under these categories are displayed in table 5 along with illustrative quotes.

Poor service delivery

Subthemes within poor service delivery include hospital postpartum practices, hospital's message about breastfeeding, counseling clients around issues related to drug use and lactation//breastfeeding, lack of follow up with client, and less value given to LCPCs.

A participant expressed frustration with hospital postpartum practices because of the lack of support for moms to breastfeed after delivery. The participant recollected an experience with a mom who had a c-section that had very limited support at the hospital as the IBCLC took a while to arrive and an electrical pump was not provided to the mom in the meanwhile. A participant also mentioned that the hospitals put out mixed messages about breastfeeding to patients which impacts their ability provide breastfeeding support. Getting the local hospital to get on board with breastfeeding was considered an important step towards solving this problem. Another participant explained that hospitals don't allow moms that are on opioid addiction treatment to breastfeed; allowing these moms to breastfeed can be a way to keep the moms from reverting to past substance use. Another challenge that LCPCs identified was follow up with clients after initial meeting. They stress the importance of prenatal education for early breastfeeding initiation. Another challenge that was identified is the lack of value placed on LCPCs. One participant mentioned that peer counselors aren't valued enough, and low compensation can also be a barrier as it can limit what LCPCs can offer.

Poor hiring strategies

A common challenge identified under organizational/institutional barriers was poor hiring strategies practiced among hospitals, clinics and other institutions. Participants pointed out the lack of minority population representation among staff, inadequate staffing, and restrictions/requirements to acquiring breastfeeding related jobs at hospitals, as some of the common flaws with hiring and recruitment.

Participants were critical of the lack of inclusivity/representation of minority populations among staff in hospitals and other organizations. According to one participant, hiring a diverse team of staff is important to be welcoming to different races and provide opportunities to minority populations. Two participants mentioned the need for more lactation staff and other providers in hospitals and communities. One participant complained that the hospital needed to hire full-time IBCLCs because moms' postpartum hospital experience has the most crucial influence on breastfeeding initiation. Another participant identified that hospitals typically look for people with a RN license in addition to breastfeeding credentials (IBCLC, CLC etc.) instead of separately hiring lactation staff, making it hard for people of color to acquire hospital jobs.

Institutional/policy constraints

Subthemes within institutional/policy constraints include low insurance coverage, time constraints, and lack of breastfeeding education/training among hospitals/organizations.

Three participants identified low insurance coverage to be a major problem which prevents them from providing the best breastfeeding support/counseling. One participant expressed frustration with how Medicaid clients may not be at liberty of receiving proper breastfeeding support due to financial constraints. The high copay associated with lactation care

was also identified as a challenge since it prevents LCPCs from helping clients. Another participant identified that non-WIC recipients are also at a disadvantage because insurance may not cover certain lactation services. Participants were also frustrated with limited amount of time available to them to see certain number of clients which can be hard to provide prenatal/postnatal counseling within said time. Another participant identified that some WIC offices in Appalachia are only open couple days a week which can be challenging to provide effective lactation support.

Table 5. Factors that limit breastfeeding/lactation support at the organization/institutional level

Theme	Illustrative quotes
Low Insurance Coverage prevents LCPCs/Hospitals from providing the best support/counseling	"Certain populations are more hurt than others because non-Medicaid populations can pay out of pocket where often Medicaid populations cannot so they're at the mercy to what's available around them and money being the difference is an issue for me" – *Private lactation consultant, IBCLC from Ohio* "I mean obviously health insurance and costs of health care is a factor and sometimes your counseling and the parent is more stressed. They realize that for example, their co pay is a hundred dollars every time they come to the hospital. So, then they're stressed about wanting to come back and get the support to meet their goal, but they also feel financially strained." -*Speech Language Pathologist, IBCLC from North Carolina, Kentucky*
Time Constraints	"Some of our WIC offices are only open one or two days a week and getting people there at the right time is a challenge. Maybe they can get there on Thursday because the boyfriend is off on Thursday but maybe that office is only open on Wednesday" -*WIC Breastfeeding Coordinator, IBCLC from West Virginia*
Hospital's message about breastfeeding	"One of our local hospitals gives very mixed messages when it comes to breastfeeding" -*Birth/Postpartum Doula from Kentucky*
Lack of breastfeeding education/training among hospital staff and other organizations	"They don't know that they're not supporting it because their staff aren't educated on breastfeeding laws or their supervisors/HR are not educated on how they can support mom/dad to return to work while breast feeding. So, when that seed is not planted early for employees, they don't feel like they have an option." -*WIC Project Coordinator from Ohio*
Lack of minority population representation among hospital staff	"There are lot of white nurses so it's very difficult when people of color are trying to learn breast feeding. It is really really important that you hire people that look like your clients, look like your patients so they know what success looks like." -*Private Lactation Counselor & Black Breastfeed group Non-profit Volunteer, CLC from Alabama*

Table 5. (continued)

Theme	Quotation example
Inadequate staffing (IBCLC's, Physicians, breastfeeding support etc.)	"The hospital does not have any IBCLCs. Well they have a nurse who has minimal training. Then the other hospital has an IBCLC who is a nurse first so she has to finish nursing duties first before she can go see a family for breastfeeding support. There are no IBCLC office hours once the client has left the hospital. She does not have the time." - *Birth/Postpartum Doula, Kentucky*
Lack of follow up with client	"So the most difficult would be subsequent contact with clients after the initial contact. They say I'm thinking about breast feeding and then I'm not going to see them again until they've delivered." -*WIC Breastfeeding Coordinator, IBCLC from West Virginia*
Hospital postpartum practices	"I remember the situation where she had a c-section…it took a while for the IBCLC to come around before I had gotten there so that's a big thing: limited help at the hospital." -*ROSE Non-profit Volunteer, CLC from Georgia*
Restrictions/Requirements to acquiring breastfeeding related jobs at hospital	"When you try to work in the hospital, they list you sometimes as P. R. N. as needed. They want you to have a RN license and they may have other nurses who are peer counselors or who have gone through breast feeding training mandated by a baby friendly designation. But you know they would rather have a nurse rather than a certified person teaching. That can be difficult." -*Private Lactation Counselor & Non-profit volunteer, CLC from Alabama*
Counseling clients around issues related to drug use and lactation/breastfeeding	"I'm going to say that the moms that are in treatment (there's so many now) that are on Subutex, Suboxone, Methadone etc., the hospital is not going to allow this mom to breastfeed and I find that a bit frustrating." -*WIC Breastfeeding Coordinator, IBCLC from West Virginia*
My lactation and breastfeeding expertise are not valued	"Value isn't really placed on a peer counselor. I think that the peer counselor position is so important because of building the relationship and peer counselors are able to do that more so than the other staff because we're available you know outside of those normal hours." *ROSE Non-profit Volunteer, CLC from Georgia*

Provider level barriers

Participants were asked to describe some of the provider level barriers that impact their ability to provide breastfeeding/lactation counseling and support. Two main categories of barriers emerged under these results: negative/misleading perceptions and lack of breastfeeding support. All the themes under these categories are displayed in table 6 along with illustrative quotes.

Negative/misleading perceptions

Subthemes within negative/misleading perceptions include biased treatment from health providers, misinformation about formula feeding, and inconsistent implementation of policies

Participants conveyed their frustration about the bias shown towards patients by providers. One participant mentioned that nurses at the hospital had bias towards people of color with bigger breasts, with the assumption that they cannot breastfeed. Providers need training to work with different body types and people of all backgrounds/conditions to remove any bias. Another participant pointed the hidden bias towards Medicaid recipients as they were treated less and given less support compared to private insurance recipients. Participants explained that sometimes providers gave out wrong information about breastfeeding to moms. One participant gave examples of healthcare providers giving inappropriate advice to mothers, suggesting them to provide formula to the baby after breastfeeding just to fill up the baby. Participants also complained that hospital policies were not followed consistently across providers which influenced whether the mom exclusively breastfeed or used formula. One participant gave an example of doctors setting their own blood sugar thresholds to decide whether the mom can breastfeed, or use should use formula, which was very inconsistent with the hospital policy.

Lack of breastfeeding support

Subthemes within lack of breastfeeding support include lack of breastfeeding education/training, support for clients with health conditions that interfere with breastfeeding/lactation, providers not being supportive of breastfeeding, and providers not being openminded about breastfeeding issues and breastfeeding in general.

Participants reported that hospital staff and organizations need mandated breastfeeding education/training. Participants gave examples of doctors and nurses not being as educated about basic breastfeeding. Another participant found it frustrating that daycare providers were not trained in breastfeeding so they're more inclined to give a bottle to the baby. Another challenge identified was lack of counseling for clients with health conditions that can interfere with breastfeeding/lactation. One participant identified that lots of women in her community had various medical conditions (thyroid, ovarian disease etc.) due to factory work exposure and that these women also had insufficient milk supply. These participants need proper counseling from providers. Five of the participants discussed problems with healthcare providers in their communities not being supportive of breastfeeding. Participants gave examples of doctors immediately suggesting mothers to give bottles/formula to the babies when they saw mothers struggling, without providing the push and support for breastfeeding. Another participant stressed the importance for the providers to ask more questions to moms regarding lactation support as opposed to undermining their confidence. Three participants mentioned that providers are not being openminded about breastfeeding and dealing with breastfeeding issues. They gave examples of the doctors 'not listening to people' and being stuck with 'few points of view', which can be a barrier. Another participant explained particularly how providers need to be more openminded to diagnosing and treating mouth issues such as lip ties and tongue ties as that can make it very difficult for the moms to breastfeed.

Table 6. Factors that limit breastfeeding/lactation support at the Provider level

Theme	Illustrative quotes
Lack of breastfeeding education/training among other providers	"We do have some doctors in our area that are not as educated in breastfeeding." - *WIC Nutrition Associate, CLC from Virginia*

Table 6. (continued)

Theme	Illustrative quotes
Other healthcare providers are not supportive of breastfeeding	"Well locally health professional support is a big problem too. We still have a lot of physicians who aren't very supportive. When the very first road bump comes along, they say, "oh well, just quit breastfeeding and here's formula" and so clients don't necessarily get good support from their OBs or pediatricians." -*WIC Regional Breastfeeding Coordinator, IBCLC from Kentucky* "The biggest thing is for health care teams to ask more questions such as "do you want to breastfeed?" We have low breast feeding rates and I'm fine with that, I can work with that but more of the blatant, very obvious knocking down the confidence of moms, where they say just give formula as opposed to asking them do you want more lactation help?" -*WIC Project Coordinator from Kentucky*
Inconsistent implementation of policies	"We have a policy that says that if the baby has a blood sugar of 35-39, then the mom can breastfeed to see if the blood sugar will come up in thirty minutes and if blood sugar is lower than 30 then obviously, they need to get an I. V. The policy says if blood sugar is 40 then it's fine, but I have some doctors that want it to be above 50. We have some that are okay with 40 and it's just depending on doctors on call that day whether the mom is going to be able to exclusively breastfeed or if she is going to have to use formula." -*Hospital provider, IBCLC from Virginia*
Biased treatment from health providers	"For example, people of color tend to have bigger breasts versus white women. If they're big breasted they're mostly augmented if that makes sense. We're talking about a woman of color, we're talking about G's, double I's. So, a lot of nurses I've worked with have it built in and say 'omg her boobs are so big, she's going to suffocate her baby'… We need to tell her these are the positions that work best for her vs us talking about, 'well I mean her boobs are really big, she cannot breastfeed.'" - *Private Lactation Counselor & Non-profit volunteer, CLC from Alabama*
Providers not being open-minded about breastfeeding issues and breastfeeding in general	"Providers need to be more open minded to corrections that need to be made if the child has any mouth issues. I mean there's just so many other issues that come with having tongue ties and lip ties. Having those changes to be made and then using that as a referral system to the dental doctors that can be beneficial." -*Health Department Home Visitor Lactation Consultant from West Virginia*
Misinformation about formula feeding	"Healthcare providers are not supportive to the point where I found that they suggest to women that they can breastfeed, but to just make sure the baby is full after breastfeeding session, they suggest providing formula." -*Lactation Consultant/Educator/Researcher, IBCLC from Ohio*
Supporting clients who have health conditions that interfere with breastfeeding/lactation	"I've got a tremendous number of women who have medical conditions now. We've got problems with thyroid; we've got problems with polycystic ovarian disease and these women are truly not making the milk. I identified this fifteen years ago." -*WIC Breastfeeding Coordinator, IBCLC from West Virginia*

Suggested changes: organizational/institutional/provider level

Participants were asked what changes they would like to see related to providing breastfeeding and lactation support at the organizational/institutional and provider level. They identified various different changes specific to their communities that fell under 15 themes that are all displayed in Table 7.

The three most mentioned changes across participants was the need for more lactation staff in OB/Peds offices, breastfeeding education/training for all providers, and physician support. Four participants mentioned the need for hospitals and OB/peds clinics to hire IBCLCs/licensed lactation staff to counsel mothers complemented with their prenatal/postnatal appointments. Five participants identified the need for mandated breastfeeding education/training for all hospital staff and providers as it is crucial for moms to get the positive message and support for breastfeeding in the prenatal and postnatal periods from healthcare providers. One participant emphasized that weight loss in newborns needs to be normalized because some providers push for formula in the first few days to get the baby back to normal weight, which is not an evidence-based method. Participants also explained how important it is for providers to support breastfeeding in a more positive approach because patients give more weight to what a doctor or nurse practitioner says compared to LCPCs.

Table 7. Suggested changes at the organizational/institutional/provider levels to optimize breastfeeding/lactation support

Theme	Illustrative quotes
Workplace policies to support breastfeeding moms	"We need to overhaul the health care system to allow extended paid maternity leave so clients can start the breastfeeding experience without that fear of added stress of 'what am I going to do when I return to work?' 'how's it going to work?' and 'who will take care of my child?' We need that, that's the highest end where we need change" -*WIC Project Coordinator from Ohio*
More respect for I.B.C.L.C. advice/expertise	"I would like to see the IBCLC credential stand alone and seen as a respected expertise specialty." -*Breastfeeding Coordinator, IBCLC from Ohio*

Table 7. (continued)

Theme	Illustrative quotes
More lactation staff (IBCLC's) in OB/Peds clinics and hospitals	"We need to have IBCLCs on staff in pediatrician offices and the fact that we don't is really ridiculous. It should be a matter of mom comes in and when there's an issue when they come to the visit, providers say 'okay now we are going to have you see our lactation consultant.' That should just be a part of it. OBs should have them on staff too so that they can do the prenatal education." -*Breastfeeding Coordinator, IBCLC from Ohio*
	"They need to hire lactation staff. There's a lot of pediatricians who don't have the time to consult a mom on how to breastfeed but also don't know how to get the mom to boost up milk so that baby is gaining weight. They just say 'you're not making enough milk, baby is getting thin, you have to feed him something' versus actually having somebody available to counsel them on how to boost the milk, to make sure they are getting enough milk and weighing the baby." *Private Lactation Counselor & Non-profit volunteer, CLC from Alabama*
Support from physicians	"I just don't want the providers to undermine what little confidence the moms have as soon as they say, 'your milk is not in yet.' If they could just not say that…I think they could change their language. If they could turn that around and say, 'your baby needs to eat often because you have colostrum which is so perfect for your baby right now, but yeah she's going to eat every thirty minutes'." -*WIC Breastfeeding Coordinator, IBCLC from West Virginia*
	"What doctor or nurse practitioner says often is considered very important information for the new parents so if they hear these positive breastfeeding messages from the health care providers, they are more likely to have a positive approach to breastfeeding." - *Lactation Consultant/Educator/Researcher, IBCLC from Ohio*
Less restrictions on RN requirement for lactation jobs	"CLC's at the hospital that don't have to have RN credentials." - *ROSE Non-profit Volunteer, CLC from Georgia*
Higher insurance reimbursement and financial incentives	"Insurance reimbursement in-patient and outpatient…If there was a financial incentive, then the hospital would do it. Pediatric offices would hire IBCLCs to see patients if we're going to get paid for it through insurance reimbursement. We would at least have freestanding outpatient lactation consultants because the big thing here is nobody wants to charge somebody a $150 for an hour consult." -WIC *Regional Breastfeeding Coordinator, IBCLC from Kentucky*
Breastfeeding friendly policies in hospital	"I would like to make policy changes in the hospital that are more breastfeeding friendly. It doesn't have to be that they need to become a baby friendly hospital, you can be breastfeeding friendly without having to go through that costly certification by putting more policies in place and more staff training. There's no reason why the nurses on the unit can't be more breastfeeding supportive." -*Hospital Provider, IBCLC from Virginia*
More positive messages about breastfeeding	"Well with my WIC parent agency in many job advertisements, I would love to see the words 'personal breastfeeding experience is a plus'." -*WIC Breastfeeding Coordinator, IBCLC from West Virginia*

Table 7. (continued)

Theme	Illustrative quotes
State licensure for IBCLC.	"Well I would like to see licensure for IBCLCs in my state and more states…I would like to see more colleges and universities having a set pathway for becoming a lactation consultant because you can't use financial aid if you're not in a program for a particular degree so that also is limiting the availability of the financial aid for the profession. I think that's a big issue…The standardized education and licensure in my state should make the transition to insurance coverage easier or even possible." -*Private Lactation Consultant, IBCLC from Ohio*
Lactation staff representation in leadership	"I would like to see as far as the higher up goes, whenever they are making changes in terms of staffing or how we do things on the unit, I would like them to consider having at least one person or representative from lactation so that we can tell them how these changes will affect the way we work on the unit with the mothers and babies." - *Hospital Provider, IBCLC from Virginia*
Restrictions on formula advertising	"I do think that advertisements from formula companies become a problem, having the free formula that you can take as a coupon with groceries at times and they'll think its free, 'well yeah I'll try it a little bit of formula'. That's already a problem so I wish there was a really better handle on the restriction on formula advertising." - *Lactation Consultant/Educator/Researcher, IBCLC from Ohio*
Availability of in-home visits from hospitals	"Hospital wise, I think it would be crucial to have more access to do in-home visits especially if you can bill it, even if it was a couple of days a week. I don't think it would need to be anything crazy but just having the availability." - *Health Department Home Visitor Lactation Consultant from West Virginia*
Better coordination among providers	"They need to look at patients like a mother baby dyad. However, the OBGYN only treats mom and so she's not thinking about the baby and then pediatrician is only thinking of baby and not thinking about the mom and so you get mismatched care. Yeah the community needs to get over it." -*WIC Project Coordinator from Ohio*
More support groups open to public	" If there was a way that we could get a support group once a week or have a hotline number for them to call saying, 'Hey you know I really need some support' and if we can get four to five participants that would participate in that, I feel like that would help. I feel that we should maybe try to open it up not only to WIC participants but also to the public." -*WIC Breastfeeding Counselor from Virginia*
Breastfeeding education/training for all hospital staff/providers	"Educating healthcare providers is really really important and it's great to keep educating providers what we do, especially hospital-based nurses. I think this is so that they help provide that positive message and support for breastfeeding." - *Lactation Consultant/Educator/Researcher, IBCLC from Ohio*

Main difficulties/barriers

Participants were asked to mention the main difficulties/barriers to providing breastfeeding support in their communities and the following themes specific to organizational/institutional challenges were noted: lack of hospital support, lack of follow up, lack of breastfeeding knowledge among providers, lack of across the board lactation coverage for Medicaid recipients, need for provider recognition of tongue ties/frenulum ties, and substance abuse. One participant mentioned that the lack of hospital support can negatively impact patient's persistence to breastfeed regardless of the prenatal education they receive from LCPCs. Another participant identified lack of follow up to be the biggest barrier, especially over the phone where it is hard to subsequently contact clients. Participants also mentioned the lack of breastfeeding support for preterm babies in the NICU. Another main challenge among participants was lack of breastfeeding knowledge among providers. Doctors were giving out misleading information to feed babies formula to gain weight, which made it harder for participants to provide lactation support. Two participants identified lack of lactation coverage under insurance. Participants gave examples of how Medicaid patients are much more limited with lactation services available to them. Another participant specifically mentioned her frustration that some insurance companies only covered basic pumps which were at limited availability at many WIC offices. One other participant identified that providers at their hospitals did not view and address tongue ties and upper frenulum ties as issues which has been a barrier for LCPCs. Lastly, substance abuse was mentioned as the biggest barrier to breastfeeding in one of the participant's community.

Discussion

The quantitative and qualitative results overlapped and had many common themes under which participants identified organizational/institutional/provider level challenges while providing breastfeeding/lactation support in Appalachia. Non-medically indicated supplementation was identified as a challenge by a majority of the participants in the survey and was also a recurring theme in the interviews under the themes of providers misinforming patients about formula feeding, physicians not showing support for breastfeeding by suggesting formula as a quick fix, and providers not following hospital breastfeeding policies consistently. This is consistent with studies that noted that nonmedically indicated supplementation is common (Boban & Zakarija-Grković, 2016; Rosin & Zakarija-Grković, 2016) and often formula is recommended to mothers by healthcare providers that see it as a quick fix (Nelson, Perrine, Scanlon, & Li, 2016).

Hospital practices, policies, interventions, postpartum practices and poor coordination were also identified as very common challenges in the survey and interviews. Participants identified subthemes such as lack of breastfeeding education/training among hospital staff, lack of lactation staff in hospitals, lack of support for patients under substance abuse or other health conditions, biased treatment, lack of hospital support groups, less availability of in-home visits, providers not being open-minded about breastfeeding issues, and restrictions on acquiring breastfeeding related jobs at hospital under this challenge. This is consistent with a study which mentions that despite the WHO's strong evidence that key hospital practices (WHO) impact breastfeeding initiation and exclusivity in the hospital and breastfeeding during post-discharge, breastfeeding friendly hospital practices are not widely implemented (Hawke, Bethany A, et al, 2013). Breastfeeding education/training for hospital staff was the most commonly suggested

intervention for addressing this challenge. According to a study, clinicians reported feeling they had insufficient breastfeeding knowledge and low levels of confidence and clinical competence in the area (Renfrew, Mary J., et al. 2006). Therefore, this can be a very beneficial intervention to increase breastfeeding among mothers. A majority of the participants also emphasized the need for more lactation staff in OB/Peds offices, and a lack of follow up which fragmented the continuity of care in breastfeeding support. This is consistent with a previous research study that found discontinuity in breastfeeding care as a barrier in New York according to healthcare professionals (Garner et al., 2016)

Institutional constraints also negatively influence proper delivery of lactation support/counseling in healthcare settings and WIC for moms that need it. Participants from the survey and interviews mentioned insurance coverage as a major barrier because of the lack of lactation services covered under Medicaid and high copays that can make breastfeeding stressful for low income people. This may explain why people with government assistance (Medicaid) and low-income people have decreased rates of breastfeeding compared to privately insured women in Appalachia (Wiener & Wiener, 2011). Participants mentioned the need for higher insurance reimbursement for low income people and financial incentives so hospitals can hire more lactation staff. Time constraints to counsel patients at WIC and hospitals were also described as a major challenge. In fact, this supports a research study which found that inadequate counseling time for breastfeeding mothers stands as a barrier for healthcare professionals (Weddig, Baker, & Auld, 2011). Lack of follow up was listed as a challenge among participants.

A concern for a commitment to diversity and inclusivity among hospital/organization staff and leadership was also important to participants in the study. This is consistent with a prior

research study that correlated racial/ethnic diversity in health-care workforce with delivery of quality care to minority populations (Betancourt 2006). Increasing underrepresented groups within the workforce can help support diversity of values of the entire population and increase cultural competency, according to participants.

State licensure for IBCLCs and higher insurance reimbursement for lactation support were described as ways to address the institutional constraints and increase financial incentives for hospitals/clinics to hire lactation staff. In fact, the American Academy of Pediatrics recommends pediatricians to employ ≥1 breastfeeding personnel on staff, especially an IBCLC (Meek, Younger, and Hatcher, 2017).

Strengths and Limitations

A strength of this study is the utilization of mixed methods which uses quantitative and qualitative data to get a better understanding of the problem and gain more depth into the complete picture. However, the study did have some limitations. Although the Appalachian population is predominantly White, both the quantitative and qualitative sample populations indicated a weakness in diversity as minorities make up 18.2% of the Appalachian population (Pollard & Jacobsen, 2018) can be attributable to the use of convenience samples. Future research should include perceptions of participants from a wide range of backgrounds/ethnicities to capture greater range of experiences. Additionally, research in the future should also try to capture participant experiences across different Appalachian states because a good amount of the sample population was clustered in Ohio. Another limitation was the utilization of a rapid analysis method to code the qualitative data which could have left out information that could have increased the dependability and credibility of the results. Response bias could have been a

concern in this study as participants self-reported in the form of interviews and surveys. This cognitive bias could have influenced responses of participants away from an accurate or truthful response.

Conclusion

People that work or volunteer related to breastfeeding/lactation in the Appalachian region are crucial to the overall effort to increase breastfeeding rates in the Appalachian region. It is important to consider organizational, institutional, and provider level barriers to breastfeeding mentioned in the study to identify appropriate interventions to implement at healthcare settings, WIC, and other organizations. The results of this study can provide background for interventions in the Appalachian region that are more integrative and supportive of the value of lactation consultants, providers, and counselors in healthcare settings.

The first steps towards addressing these barriers should incorporate an intervention that focuses on mandating breastfeeding education/training for hospital staff and all providers that work with prenatal and postpartum people in order to include them in the efforts to spread positive messages about breastfeeding and increase support for the mother-infant dyad. Second, the Appalachian region needs more lactation staff in clinics and hospitals to counsel people on breastfeeding/lactation. Third, it is also necessary to enhance diversity among hospital staff while incorporating various interventions at the organizational/institutional levels.

In future research, it is important to gain a better understanding of how the changes suggested by participants can ultimately improve breastfeeding rates in Appalachia. It is important to evaluate interventions at the organizational/institutional level to measure their impact on enhanced lactation support and counseling in Appalachia.

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Appendix 1

Supporting families in Appalachia with breastfeeding and lactation

Thank you for your interest in completing this survey!

The purpose of this research study is to learn about the experiences of people who support families in Appalachia with breastfeeding and lactation, and to explore some of the challenges they experience. You are being asked to take part in this research study because you support breastfeeding and lactation in the Appalachian Region.

Being in a research study is completely voluntary. You can choose not to be in this research study. You can also say yes now and change your mind later.

If you agree to take part in this research, you will be asked to complete an online survey. Your participation in this study will take about 15-20 minutes. We expect that 200-300 people will take part in this research study.

You can choose not to answer any question you do not wish to answer. You can also choose to stop taking the survey at any time. You must be at least 18 years old to participate. If you are younger than 18 years old, please stop now.

The possible risks to you in taking part in this research are: Feeling uncomfortable when thinking about challenges you face in your work or your experiences with infant feeding.

To protect your identity as a research subject no identifiable information will be collected.

If you have any questions about this research, please contact Stephanie Martin at 919-843-2719 or emailing stephaniemartin@unc.edu or abnunc@gmail.com. If you

have questions or concerns about your rights as a research subject, you may contact the UNC Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

- ◯ I consent
- ◯ I do not consent

Demographic Characteristics

What is your age?

- ◯ Less than 18 years old
- ◯ 18-24 years old
- ◯ 25-34 years old
- ◯ 35-44 years old
- ◯ 45-54 years old
- ◯ 55-64 years old
- ◯ 65 years old or older

What is your gender?

Where do you live?

What is the highest degree or level of school you have completed? (If you're currently enrolled in school, please indicate the highest degree you have received)

- ◯ Less than a high school diploma
- ◯ High school degree or equivalent (e.g. GED)
- ◯ Associate degree (e.g. AA, AS)
- ◯ Bachelor's degree (e.g. BA, BS)
- ◯ Master's degree (e.g. MA, MS, MSN, MPH)
- ◯ Doctoral degree (e.g. DNP, MD, DDS JD, PhD, EdD, etc)

Which categories describe you? Select all boxes that apply. Note: You may select more than one group

- ☐ American Indian or Alaska Native
- ☐ Asian

- [ ] Black or African American
- [ ] Hispanic, Latino, or Spanish
- [ ] Middle Eastern or North Africa
- [ ] Native Hawaiian or Pacific Islander
- [ ] White
- [ ] _____ Another race, ethnicity, or origin (please specify)

What is your current employment status?

- ◯ Employed full time (40 or more hours per week)
- ◯ Employed part time (up to 39 hours per week)
- ◯ Unemployed and currently looking for work
- ◯ Unemployed and not currently looking for work
- ◯ Student
- ◯ Retired
- ◯ Self-employed
- ◯ Unable to work

Are you a health professional? (for example, work in medicine, nursing, or allied health)

- ◯ Yes
- ◯ No

If yes, are you a:

- [ ] Advanced practice nurse (APN) such as a nurse practitioner or nurse midwife
- [ ] Certified professional midwife (CPM)
- [ ] Chiropractor
- [ ] Community health worker
- [ ] CranioSacral therapist
- [ ] Doula
- [ ] Dentist
- [ ] Health educator
- [ ] International Board Certified Lactation Consultant (IBCLC)

- [ ] Occupational therapist
- [ ] Physical therapist
- [ ] Physician (MD, DO)
- [ ] Physician Assistant (PA)
- [ ] Registered Dietitian (RD)/Registered Dietitian Nutritionist (RDN)
- [ ] Registered Nurse (RN)
- [ ] Speech language pathologist
- [ ] _____ Other (list)

What is your profession?

_____

Do you do work (paid or volunteer) related to breastfeeding and lactation?

- [ ] Yes, currently **employed** related to breastfeeding and lactation
- [ ] Yes, currently **volunteer** related to breastfeeding and lactation
- [ ] Yes, **in the past have been employed** related to breastfeeding and lactation
- [ ] Yes, **in the past have volunteered** related to breastfeeding and lactation
- [ ] No, have not worked or volunteered related to breastfeeding and lactation

How many years have you been working or volunteering related to breastfeeding and lactation?

- ◯ Less than 1 year
- ◯ 1-2 years
- ◯ 3-5 years
- ◯ 6-10 years
- ◯ 11-15 years
- ◯ 16-20 years
- ◯ 20 or more years

Is the work that you do related to lactation and breastfeeding based in Appalachia?

- ◯ Yes

○ No

Where do you work on breastfeeding and lactation?

Where in Appalachia do you work? (can select more than one)

- ☐ Alabama
- ☐ Georgia
- ☐ Kentucky
- ☐ Maryland
- ☐ Mississippi
- ☐ New York
- ☐ North Carolina
- ☐ Ohio
- ☐ Pennsylvania
- ☐ South Carolina
- ☐ Tennessee
- ☐ Virginia
- ☐ West Virginia
- ☐ Other

Do you:

Select all boxes that apply.

- ☐ Provide direct lactation consulting, counseling, or support to individual clients/patients
- ☐ Offer breastfeeding or lactation education, information, and promotion to patients, clients, or families
- ☐ Manage or implement programs related to breastfeeding and lactation
- ☐ Conduct research related to breastfeeding and lactation
- ☐ Train other providers, program staff, or students in lactation and breastfeeding
- ☐ Other (please specify)

Where do you work/volunteer related to breastfeeding and lactation?

- [ ] Hospital
- [ ] Private practice
- [ ] Midwifery practice
- [ ] Pediatric practice
- [ ] WIC
- [ ] County health department
- [ ] Non-profit organization
- [ ] School/educational institution
- [ ] _____ Other (please specify)

Experience providing breastfeeding/lactation support

How confident do you feel in your ability to provide evidence-based breastfeeding and lactation support or information?

- ◯ Not at all confident
- ◯ Not very confident
- ◯ Somewhat confident
- ◯ Very confident

How effective do you think you are at helping your clients or program participants reach their personal breastfeeding and lactation goals?

- ◯ Not at all effective
- ◯ Not very effective
- ◯ Somewhat effective
- ◯ Very effective

Breastfeeding/lactation credential

Do you have any of the following certifications or experiences related to breastfeeding and lactation? ***Select all boxes that apply.***

	Currently have	Had previously
Breastfeeding USA Counselor	☐	☐
CBC	☐	☐
CLC	☐	☐
CLE	☐	☐
CLS	☐	☐
IBCLC	☐	☐
LEC	☐	☐
La Leche League Leader	☐	☐
WIC Breastfeeding Peer Counselor	☐	☐
Other (please specify)	☐	☐

Do **<u>you personally experience</u>** any of the following challenges when providing breastfeeding/lactation information or support to your clients/patients/participants? (check all that apply)

Individual Factors

- ☐ Lack knowledge/skills to support clients effectively
- ☐ Lack of confidence
- ☐ Challenges with cross-cultural communication/language barriers

Health constraints/providing specific support

- ☐ Supporting clients with infants who are preterm, low-birth weight, or have other health conditions
- ☐ Supporting clients who have health conditions that interfere with breastfeeding/lactation
- ☐ Supporting overweight and obese clients
- ☐ Supporting clients with concerns about milk supply issues
- ☐ Issues around expressing, storing, handling, and feeding human milk
- ☐ Issues around sharing/acquiring human milk
- ☐ Feeding multiples
- ☐ Counseling clients around issues related to drug use and lactation/breastfeeding

Occupational context/institutional constraints

- [ ] Lack of coordination among other providers and institutions (including lack of referrals, lack of awareness of services by other providers, or delayed follow up, among others)
- [ ] Hospital practices, policies, or interventions during labor and delivery (Pitocin, epidurals, forceps, vacuum extractions, cesarean sections)
- [ ] Hospital postpartum practices (lack of skin-to-skin, not rooming-in, swaddling, use of pacifiers, use of nipple shields)
- [ ] Non-medically indicated supplementation
- [ ] Discharge packs provide formula
- [ ] Other health care providers are not supportive of breastfeeding
- [ ] Lack of administrative support
- [ ] Inadequate staffing
- [ ] Time constraints
- [ ] My lactation and breastfeeding expertise is not valued

Social Constraints

- [ ] Clients are not interested in breastfeeding/do not want to breastfeed
- [ ] Breastfeeding is not viewed as the normal way to feed infants
- [ ] Clients' partners, families, or social networks are not supportive of breastfeeding
- [ ] Challenges connecting/reaching clients/participants for follow up or retaining clients/participants in programs and services

Now, please choose the biggest challenge that **you personally experience** when providing breastfeeding/lactation information or support to your clients/patients/participants?

- ○ » Lack knowledge/skills to support clients effectively
- ○ » Lack of confidence
- ○ » Challenges with cross-cultural communication/language barriers
- ○ » Supporting clients with infants who are preterm, low-birth weight, or have other health conditions
- ○ » Supporting clients who have health conditions that interfere with breastfeeding/lactation
- ○ » Supporting overweight and obese clients
- ○ » Supporting clients with concerns about milk supply issues
- ○ » Supporting clients with issues around expressing, storing, handling, and feeding human milk

- ○ » Supporting families with issues around sharing, acquiring, or donating human milk
- ○ » Supporting clients with multiples
- ○ » Counseling clients around issues related to drug use and lactation/breastfeeding

- ○ » Lack of coordination among other providers and institutions (including lack of referrals, lack of awareness of services by other providers, or delayed follow up, among others)
- ○ » Hospital practices, policies, or interventions during labor and delivery (Pitocin, epidurals, forceps, vacuum extractions, cesarean sections)
- ○ » Hospital postpartum practices (lack of skin-to-skin, not rooming-in, swaddling, use of pacifiers, use of nipple shields)
- ○ » Non-medically indicated supplementation
- ○ » Discharge packs provide formula
- ○ » Other health care providers are not supportive of breastfeeding

- ○ » Lack of administrative support
- ○ » Inadequate staffing
- ○ » Time constraints
- ○ » My lactation and breastfeeding expertise is not valued
- ○ » Clients are not interested in breastfeeding/do not want to breastfeed
- ○ » Breastfeeding is not viewed as the normal way to feed infants
- ○ » Clients' partners, families, or social networks are not supportive of breastfeeding
- ○ » Challenges connecting/reaching clients/participants for follow up or retaining clients/participants in programs and services

Do **clients/participants/families** in your community experience any of the following challenges related to breastfeeding/lactation? (check all that apply)

Individual factors

- ☐ Lack of information/knowledge about breastfeeding
- ☐ Lack of confidence in their ability to breastfeed
- ☐ Lack of information about normal infant behavior (cues, crying, and sleep patterns)
- ☐ Concerns about milk insufficiency
- ☐ Physical challenges (nipple pain, cracked nipples, mastitis)
- ☐ Challenges with continued breastfeeding
- ☐ Mental health/stress
- ☐ Physical health
- ☐ Challenges related to overweight or obesity

- [ ] Lack of time
- [ ] Employment
- [ ] Drug use
- [ ] Negative attitudes about breastfeeding
- [ ] Negative previous experiences with breastfeeding/lactation
- [ ] Accessing human milk for their baby (either formally or through informal sharing)

Interpersonal factors

- [ ] Lack of partner support
- [ ] Lack of family support
- [ ] Lack of support from friends and peers
- [ ] Experiencing abuse or violence

Health system related factors

- [ ] Hospital policies and practices interfered with breastfeeding initiation
- [ ] Health care providers are not supportive of breastfeeding
- [ ] Biased treatment from health providers
- [ ] Difficult to access to lactation support (i.e. distance)
- [ ] Cost of lactation support
- [ ] Lack of support after hospital discharge
- [ ] Routine supplementation

Policy Issues

- [ ] Lack of parental leave
- [ ] Workplace policies, other than parental leave, that are not supportive of breastfeeding/lactation
- [ ] Influence of formula industry

Social/societal/community

- [ ] Breastfeeding is not the social norm
- [ ] Lack of family support
- [ ] Environment does not welcome breastfeeding in public
- [ ] Lack of peer support
- [ ] Racism
- [ ] Sexism
- [ ] Discrimination of gender identity
- [ ] Influence of formula industry

Please choose the biggest challenge of breastfeeding and lactation **clients/participants/families** in your community experience:

- ○ » Lack of information/knowledge about breastfeeding
- ○ » Lack of confidence in their ability to breastfeed
- ○ » Lack of information about normal infant behavior (cues, crying, and sleep patterns)
- ○ » Concerns about milk insufficiency
- ○ » Physical challenges (nipple pain, cracked nipples, mastitis)
- ○ » Challenges with continued breastfeeding
- ○ » Mental health/stress
- ○ » Physical health
- ○ » Challenges related to overweight or obesity
- ○ » Lack of time
- ○ » Employment
- ○ » Drug use
- ○ » Negative attitudes about breastfeeding
- ○ » Negative previous experiences with breastfeeding/lactation
- ○ » Accessing human milk for their baby (either formally or through informal sharing)
- ○ » Lack of partner support
- ○ » Lack of family support
- ○ » Lack of support from friends and peers
- ○ » Experiencing abuse or violence
- ○ » Hospital policies and practices interfered with breastfeeding initiation
- ○ » Health care providers are not supportive of breastfeeding » Biased treatment from health providers
- ○ » Difficult to access to lactation support (i.e. distance)
- ○ » Cost of lactation support
- ○ » Lack of support after hospital discharge
- ○ » Routine supplementation in hospitals
- ○ » Lack of parental leave
- ○ » Workplace policies, other than parental leave, that are not supportive of breastfeeding/lactation
- ○ » Influence of formula industry

- ◯ » Influence of formula industry
- ◯ » Breastfeeding is not the social norm
- ◯ » Lack of family support
- ◯ » Environment does not welcome breastfeeding in public
- ◯ » Lack of peer support
- ◯ » Racism
- ◯ » Sexism
- ◯ » Discrimination of gender identity
- ◯ » Influence of formula industry

Is there anything else that you would like to share with us?

In the future, would you be willing to be contacted about participating in a longer interview either over the phone or in person? (Note you will be re-directed to a new webpage and your personal information will not be connected to your responses here).

- ◯ Yes
- ◯ No

Appendix 2

Semi-structured phone interview guide

Thank you for agreeing to talk with me today. We are interested in hearing about the experiences of people who support families in Appalachia with breastfeeding and lactation, and to explore some of the challenges they experience.

How long have you worked or volunteered related to breastfeeding?

Do you have any breastfeeding or lactation credentials? Which ones?

Have you had more than one position related to breastfeeding and lactation? If so, what are the different kinds of positions that you have had related to breastfeeding and lactation?

Can you tell me about your professional or volunteer work that you currently do related to breastfeeding lactation?

- Where do you work?
- How long have you worked/volunteered there?
- Who are your clients or program participants?
- What is your role/position?
- What do you do related to breastfeeding and lactation?
- Where and when do you see family members (pregnancy, birth, in hospital, after discharge, WIC clinic, etc)

What do you like most about providing lactation support to families?

What makes it difficult to provide lactation support to families?

What are factors that facilitate your ability to provide support to families?

- Organization/institute
- Other providers
- Community/social factors
- Families

Are these different in different situations? Can you give me some examples?

What are factors that limit your ability to provide support to families?

Organization/institute
Other providers
Community/social factors
Families

Are these different in different situations? Can you give me some examples?

Has your ability to provide support and management of breastfeeding problems changed over time and if so, how and why?

Are there are any breastfeeding or lactation issues that you do not feel comfortable supporting/managing? Which? Why?

What are changes you would like to see related to providing breastfeeding and lactation support?

Organization/institute
Other providers
Community/social factors
Families

What do you see as the biggest barriers to breastfeeding in your community?

Are these different among different groups? How?
Can you give me examples of how these barriers impact breastfeeding?
What do you think could be done to address these barriers?

Are families in your community identifying breastfeeding problems and seeking help?

Why or why not?
What prevents them from seeking support?

Are you a parent?

How does your own experience with infant feeding influence your interactions with families?

Is there anything else you think is important to mention that we haven't talked about?

What is your age?

What is the highest level of education you have completed?

What is your gender?

What is your race/ethnicity?